Key Findings of CCI Asia Survivor Survey

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CCI Asian Survivors Network

For 15th CCI Asia Conference
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Survey Objectives

• Find out the level of understanding of survivors about late effects of childhood cancer

• Briefly assess the quality of survivors’ life after they had cancer

• Encourage survivors to take self-care of their health conditions, including going to follow-ups

• Provide a basis for advocacy for better education of late effects provided to survivors
Scope of Coverage

• Childhood cancer survivor (CCS) in Asia, who is cancer-free for at least 5 years

• Currently aged 18 and above

• From August 2022 to Feb 2023, CCI Asia received responses from **297 CCSs, 14 countries/jurisdictions** through an online questionnaire
  • 54% Male, 46% Female
  • 88% from LMIC, 12% from HIC
Key Findings – Late Effects
76% of CCSs were aware of late effects before this study

- It's common to receive **late effects information from multiple channels.** Besides the medical team and allied health professionals, **29% of CCSs** reported to **learn about late effects from other survivors** (via hospital visits/virtual sharing).
- Among CCSs who are aware of late effects, **only 68%** were told about late effects **before completing treatments.**
Lack of awareness for follow-up on long term effects is a concern

Do you attend any follow-up consultations / treatments for your late effects?

- Yes 63%
- No 37%

Reasons for not attending follow-up:
- 41% - Do not think it is necessary
- 32% - Not aware of the need
- 19% - Financial limitations
- 14% - Distance problem
- 11% - Hectic daily schedule
- 5% - Others

Places for follow-up:
- 56% - Out-patient clinic at hospital that gave treatments
- 32% - Survivor-centric clinic
- 30% - NGO
- 10% - General clinic outside the hospital that gave treatments
Majority of CCSs want to learn more about late effects not just for themselves but also sharing with peers

Would like to know more about late effects

69%

- Prevention/early detection of relevant late effects: 58%
- Verify self-understanding: 39%
- Share with survivors: 38%
- Just being curious: 34%
- Not sure if current problems are related to previous treatments: 32%
- Others: 0%

Do not want to know more about late effects

31%

- No health problems, knowledge of late effect is not necessary: 46%
- Enough understanding: 34%
- Do not want to look back to CC experience: 31%
- Others: 0%
In-person interactions are preferred by CCSs for late effects consultation/education, while CCSs are keen to get information from peers.

**Whom do you prefer to ask/consult about late effects?**
(multiple options accepted)

<table>
<thead>
<tr>
<th></th>
<th>Doctors</th>
<th>Other Survivors</th>
<th>Social Workers</th>
<th>Nurses</th>
<th>Clinical Psychologists</th>
<th>Child Life Specialists</th>
<th>Caregivers</th>
<th>Teachers in Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage</td>
<td>78%</td>
<td>28%</td>
<td>25%</td>
<td>18%</td>
<td>17%</td>
<td>11%</td>
<td>8%</td>
<td>5%</td>
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**Whom do you prefer to ask/consult about late effects?**
(multiple options accepted)

<table>
<thead>
<tr>
<th></th>
<th>Survivors’ Meeting</th>
<th>F2F Consultation with Medical Professionals</th>
<th>Health Seminar</th>
<th>Survivors Health Booklet</th>
<th>Mobile Application</th>
<th>Email</th>
<th>Social media</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage</td>
<td>49%</td>
<td>47%</td>
<td>40%</td>
<td>24%</td>
<td>22%</td>
<td>19%</td>
<td>18%</td>
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Key Findings – Quality of Life
CCSs seem to be able to maintain relationships with people around them and self-esteem despite having cancer.

- Situations vary by diagnosis. **Above 70% of survivors with retinoblastoma** have ever **lost relationship** with friends/partners and **55% of retinoblastoma survivors have ever felt ashamed** because they had cancer.
- **71% of survivors with brain/spinal cord tumor** have ever **felt guilty** because they are a survivor while others were not as lucky.
However, CCSs still experience moderate level of discrimination, rejection for jobs and anxiety about future.

- Similarly, situations vary by diagnosis. **More than half of survivors with bone tumor or retinoblastoma** reported to have experienced **discrimination** and **felt hopeless about future** because they had cancer in the past.
- Survivors with **bone tumor do not have difficulties in finding jobs** but it is a challenge for those with brain/spinal cord tumor or retinoblastoma.
Close to half of CCSs lost interest of things they love to do and often experience fear and anger with no reasons for it.

Did you find yourself losing interest in activities you previously found enjoyable or liked doing?
- Yes, 46%
- No, 54%

Are there occasions you experience fear or anger, with no real reasons for it?
- Yes, 42%
- No, 35%
- Not Sure, 22%

- Majority of survivors with bone tumor (62%), brain/spinal cord tumor (79%) and retinoblastoma (55%) lost interest in activities they enjoyed doing, most likely because of loss in physical ability.
- 82% of Retinoblastoma survivors often experience fear or anger with no real reasons for it.
Other assessments of CCS’s quality of life (on scale of 1-10)

- **Fatigue**: 6.1
- **Sleep Quality**: 6.7
- **Musculoskeletal Complications**: 6.0
- **Body Image Concern**: 6.1

- Level of satisfaction **varies by diagnosis**.
- Notably, survivors with **lymphoma, bone tumors or retinoblastoma** have bigger concern over **body image**.
- **Lymphoma and brain/spinal cord tumors’** survivors **suffered more in fatigue** compared to others.
- **Leukemia survivors** fare **better in** overall assessment.
Survivors lack awareness of the essence of maintaining alcohol intake control and avoiding smoking

- When asking survivors about actions to take in order to stay healthy, only 57% and 34% chose “No smoking” and “Maintain minimal intake of alcohol” respectively.
- This finding signifies the need for educating survivors of maintaining a good lifestyle, as they are more vulnerable physically compared to ones without cancer / undergoing intensive medical treatment.

<table>
<thead>
<tr>
<th>Action</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Healthy diet</td>
<td>84%</td>
</tr>
<tr>
<td>Regular exercise</td>
<td>73%</td>
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<tr>
<td>No smoking</td>
<td>57%</td>
</tr>
<tr>
<td>Maintain minimal intake of alcohol</td>
<td>34%</td>
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Which of the following actions should a survivor take to stay healthy? (multiple options accepted)
Conclusion
Key Takeaways & Way Forward

• There is still room for enhancing late effects education to survivors, while majority of them are willing to know more:
  • Possibilities of having late effects after receiving treatment
  • Importance of long-term follow-up and maintaining a healthy lifestyle
  • Relevance and accuracy of information shared among survivors themselves
  • Direct/in-person interactions as the preferred mean, instead of handing out information through digital channels

• Besides face-to-face medical consultation, survivors meeting are highly valued by survivors where they can connect and share stories with people with similar experiences

• Maintaining a survivor network and connecting it to medical teams and relevant support groups is crucial
Acknowledgement:

• CCI Asia Regional Committee

• Dr Ramandeep Arora (Oncologist, India)

• CCI Member Organizations

• CCI Asian Survivor Network Working Group & Ms. Genevieve Tan (SCCS, Malaysia)
Thank You!

We Care, We Share, and We Connect!